Developmental Disabilities Council Meeting Minutes Wednesday, November 9, 2016 Margaret M. O'Neill Building, Dover, DE A.I. DuPont Hospital, Conference Room 2C, Wilmington, DE

Members Present: Barbara Monaghan (chairperson), Maitri Campbell, Alex Eldreth, Terri Hancharick, Rick Kosmalski, HarrietAnn Litwin, Katie Macklin, Karen McGloughlin, Daniese McMullin-Powell, Carrie Melchisky, Joseph Merritt, Jr., Beth Mineo, Angela Mitchell, Shawn Rohe, Steve Yeatman

Members Absent: Carol Barnett, Angela Ehst, Alvin Emory, Jr., Karen Gallagher, Laura Greene, Michael Harris, Brian Hartman, Esq., Katie Howe, Diann Jones, Nancy Lemus, Debra McCann, Sue Ellen Powell, Jill Scannell, Steve Slotkin

Staff: Pat Maichle, Kristin Harvey, Stefanie Lancaster, Emmanuel Jenkins

Guests: Bill Monaghan, Bill Powell, Victoria Counihan (Deputy Attorney AG)

- **I.** Call to Order Barbara Monaghan called the meeting to order at 6:04 p.m.
- **II. Approval of Minutes** Joseph Merritt, Jr., made a motion to approve the minutes as submitted. Daniese McMullin-Powell seconded. The minutes were approved by Council.
- III. Approval of Agenda HarriettAnn Litwin asked that her presentation be moved up within the agenda to after the 5 Minute Public Comment Period. Karen McGloughlin made the motion to approve the agenda with this change. Daniese McMullin-Powell seconded. The agenda was approved by Council.
- IV. 5 Minute Public Comment Period Daniese McMullin-Powell stated that she recently took part in a protest with ADAPT of the Judge Rotenberg Center (JRC) in Canton Massachusetts. JRC is the only remaining facility/school that used electric shock as an aversive "treatment" to attempt to modify behavior in kids with disabilities. Some of the behaviors are refusing to remove your coat, standing up when told to remain seated, hand flapping (sometimes done by people with autism). The FDA has been trying to ban the devices that deliver these shocks. JRC has been under investigation for these "treatments" for injuries and deaths that have occurred at that facility. Some other aversive punishments also include forced ammonia inhalation and white noise helmets to eliminate sounds. Daniese stated we must not stand for these abuses to continue to kids with autism

or any other disability.

Bill Monaghan stated he did his good deed for the day while voting yesterday. A friend of his who was 100 years old wanted to vote but their assisted living facility wouldn't take them. He took her to vote. He was in there with her because she was blind and needed assistance while voting.

V. Chair's Report – Barbara stated she recently saw the movie "Bottom Dollar" which discusses the struggle of people who want to get jobs when they come out of a sheltered workshop atmosphere. Barbara felt this was a very inspiring movie.

Jamie Wolfe is working with Delaware People First to develop a support group for people with disabilities who've had cancer as well as an upcoming dance.

VI. Staff Report – Pat reported the following:

- In the member's informational packets, a DDC Meeting Date Calendar for 2017 was distributed. Evening meetings will be at the Department of Health and Social Services (DHSS) Herman Holloway Campus in New Castle, not at Nemours. Nemours is unable to accommodate us anymore. DHSS has ample parking and is accessible. Members were encouraged to put the meeting dates on their calendars now.
- LIFE Conference brochures are now available. If you are interested in attending this year's conference, please let Stefanie know so that she may register you. DDC will pay for members to attend. Pat, along with a few other individuals, will be presenting Secretary Rita Landgraf with a thank you for all her hard work over past 8 years that she has served as the Secretary for Health and Social Services.
- The National Association of Councils on Developmental Disabilities (NACDD) has announced the opportunity for one lucky person to receive NACDD's Scholarship to attend the National Leadership Consortium on DD (NLCDD) training Institute at the University of Delaware. This training is offered in January and June. Anyone interested should apply by contacting Donna Meltzer at dmeltzer@nacdd.org.
- The National Center for Cultural and Linguistic Competence (NCCC) at Georgetown University has received a grant from AIDD to form Communities of Practice in 10 states to work together to address these issues. NACDD has shared their support of this effort.
- NACDD has received a grant from United Healthcare for support of the Partners in Policymaking Program. They want to take look at program to see how we can grow it. Pat is thinking of joining this advisory group.
- The Department of Justice (DOJ) has released a statement on guidance of how the ADA and Olmstead apply to employment services and settings.
 When the ADA was first established and signed, the language in it pertained to predominately residential settings. However, more recently the DOJ, with support of many in the disability community, has begun to apply the

ADA's integration mandate and the Olmstead decision to both publicly-funded employment services and settings and facility-based programs in an effort to assist state and local governments in ensuring that the employment supports and services provided to individuals with disabilities are in compliance with the ADA and Olmstead.

- The DDC has received a thank you note from National Alliance on Mental Illness (NAMI) for our continued support via sponsorship to the NAMI Conference.
- The Department of Education and Governor's Advisory Council for Exceptional Citizens is attempting to bring LaDerick Horne to Delaware. LaDerick is phenomenal man and has a great story to share about his history and what he does now writing manuals for teachers.
- Emmanuel reported that the DDC Facebook page currently has 792 likes which is up 9 likes since the September meeting. The goal is still to hit 1000 by December 31st. Twitter is currently at 201 followers which is up by 8 new followers since September. The only active hashtag is for the LIFE Conference. #lifeconference2017. A hashtag will be coming out soon regarding Junior Partners in Policymaking 2017 program.

VII. Financial Report

Financial Advisory Committee Report – Carol Barnett was not present. Pat reported that there is \$59,620 remaining in 2016 funds to be obligated prior to September 30, 2017. Committees need to begin to brainstorm some project ideas so that these funds can be obligated. The report was approved as submitted.

VIII. Current Business

- 1. Legislative Update Pat reported that the Legislative Planning Committee has begun to develop a legislative agenda for the new administration. The next meeting will be held on November 14th at 2 p.m. at the Appoquinimink State Service Center. A list of 41 items has been developed to choose from. The Committee needs to choose 10 issues to work on for the upcoming year. A document will be handed out at the LIFE Conference to introduce our collaborative agenda for the upcoming year.
- 2. SDM Committee Update The Supported Decision Making Committee was required by SB 230 that passed this last session. The committee will meet a total of four times. A list of recommendations will be provided to DHSS on how to best distribute information on this topic to the public. One of the prime focuses is on education on this option along with other options available to individuals in Delaware who need support making decisions.
- 3. HCBS Transition Plan Update The Center for Medicaid and Medicare Services has requested public comment on additional reforms and policy options the agency can consider accelerating access to HCBS. CMS has given their conditional approval to DE which includes a list of what Division of Medicaid and Medicare Services has to make changes to and resubmit. These changes can be viewed on DMMA's website. All of the self-assessments have been received and are now in desk review. Minimal changes were found.

Terri Hancharick stated that the numbers the report shows are not accurate as no assessments have been done for those living in group homes.

IX. Committee Reports

- **1. Membership** Karen McGloughlin reported the following changes:
- * Diann Jones has served two consecutive terms. Therefore, must take a year rotating off the Council. We will recognize her service at the January meeting with the presentation of a plaque.
- * Alvin Emory was returning from his leave of absence due to his wife's medical condition. After her passing he had planned to return to meetings. However, his health has required the need for heart surgery. He is requesting another six months of leave due to his own health issues. Council Approved.
- * Deb McCann is requesting a six month medical leave of absence for her health issues. Council Approved.
- * Angie Ehst has had some significant health issues and is also requesting a medical leave of absence for six months. Council Approved.
- * Steve Yeatman questioned if these leave of absences affected our quorum. Victoria will check on this and report back to Council.
- 2. Children & Families Alex Eldreth reported that at the October meeting, the committee reviewed its goals in the new strategic plan. They began discussions on how to best prioritize their efforts. At the November meeting, Steve Groff and Lisa Zimmerman from DMMA came to discuss goal #2 regarding nutrition and exercise along with childhood obesity in individuals with disabilities along with access to accessible exercise equipment. They did more listening and were very receptive to our ideas. We are looking for ways to low cost or no cost healthcare along with partnerships with state agencies and others.
- **3. Policy & Law DRAFT Statement on Assisted Suicide** Terri Hancharick reported:
 - * She recently attended an SDM Summit that the DDC helped pay for. There were 30 people in attendance from around the world and country. They had panel discussions to discuss Supported Decision Making not only from guardianship level but also for those coming out of institutions. They had experts on housing, employment, education, etc.
 - * A position statement has been developed to relay the DD Council's position on Assisted Suicide. A copy was provided to all members in attendance. After little discussion, the statement was approved by Council and will need to be posted to the DDC's webpage.
- 4. Adult Issues Terri reported the Adult Issues committee is currently working with the Katie Macklin with the Alzheimer's Association regarding the intersection with Down syndrome. Dr. Mary Stephens runs a Down Syndrome clinic with Christiana Care. They are introducing DDC to the Swank Memory Center. They are working to answer the following: "How can we approach this issue with people with Down syndrome and Alzheimer's as they reach ages 50-

60? How can we best collect the data? How can we get PR done for this effort?" Pat intends to bring a group of parents together that have adult children with Down Syndrome. Pat thanks Katie for helping with this. Delaware can be a leader in this issue.

5. Partners Oversight

- 1. Partners 2016 Final Kristin gave a quick overview of the Partners 2016 program. There were 22 applicants of which 14 completed the program. 11 were female and 3 male. 5 were parent advocates of children ranging age 3 14. 9 were self-advocates. Overall, this was a great group of individuals who graduated in September.
- **2. Jr. Partners 2017 Update** The next planning meeting will be held at Delaware State University to look at the dorm rooms and begin the process of recruitment. A copy of the application and brochure are in each Member packets.
- 6. Consumer Caucus Joseph Merritt announced that the next Consumer Caucus meeting will be held on November 19th beginning at 9:30 a.m. at the ChesDel Restaurant. Please let DDC Staff know if you would like to attend.

X. New Business

1. Presentation by Harriet Ann Litwin – WIOA –

HarrietAnn Litwin presented information to the DD Council about the Delaware Division of Vocational Rehabilitation (DVR) and the Workforce Innovation and Opportunity Act (WIOA). DVR works to provide individualized services to employers and people with disabilities, developing career pathways that link qualified employee to jobs, resulting in greater independence and a more inclusive workplace.

WIOA, which was signed into law July 22, 2014, is designed to help job seekers access employment, education, training, and support services to succeed in the labor market and to match employers with the skilled workers they need to compete in the global economy.

WIOA requires extensive reforms. The three most important reforms, specific to VR include: 1) Requires states to strategically align workforce development programs. 2) Core programs are required to report on common performance indicators that provide key employment information. 3) Improves services to individuals with disabilities.

Handouts were provided and are available. For more details, please visit DVR's website at www.dvr.delawareworks.com to read more about WIOA and its efforts in Delaware.

2. Request for Medical Leave of Absence – This was discussed previously during the Membership report.

- 3. Request from Laura Greene Education Laura Greene has requested the Council's support for an education program through Leadership Delaware. Leadership Delaware recruits and mentors outstanding young Delawareans who have the "stuff of leadership", the potential, desire, and courage to excel at community, nonprofit, political, professional and corporate leadership within the First State. This enables individuals to rise to the highest levels of leadership in our state. Laura is requesting \$4,500 in support of this effort. Pat stated the Council can approve any, all or none of this request. There was some discussion regarding how much the Council has approved previously for things like this for regards to members. Pat stated the most approved was \$1,000. Daniese asked what benefit to the Council would there be. Pat said potentially she could be Council chair or join NACDD board member. After lengthy discussion, it was decided to not approve this at this time.
- **4. Future Speakers** Upcoming speakers are as follows:
- The January DDC Meeting Sara Weir from the NDSS will come to speak about the ABLE Act.
- March Laura Strmel will come to speak about how organization can change their business practices to better serve those who want to go to work.
 We may also have Cheryl Bates-Harris to speak about the new "Bottom Dollar" video in May.
- July Families Speaking Up members request to come to speak to the Council about segregated settings.
- September Brian Freedman from the CDS to speak about the work that they are doing on Autism.
- **4. Annual Calendar of DDC Meetings** This was previously discussed in the staff report.
- **XI.** Other Council Business No other Council business at this time.
- **XII.** Adjournment The meeting was adjourned at 8:05 p.m.